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ABSTRACT

This publication addresses the advocacy, counseling, and case management skills needed by the independent living counselor and includes a case management tool which underscores the importance of needs assessment, goal setting, and program monitoring. Based on a review of pertinent literature, the booklet contains five sections. The first secion details the independent living philosophy. This section is followed by sections describing the human and legal rights of handicapped persons and the communications skills needed by counselors. The fourth, and major, section of the publication explains case management skills needed by the counselor. According to this section, the counselor must be a case finder; needs analyst; service arranger, provider, and coordinator; goal attainment specialist; and support system designer. A case management form for independent living counseling is provided. The final section of the publication contains conclusions about the counselor role derived from the research effort and recommendations of how the counselor can fulfill them. (KC)

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THE ROLE OF THE INDEPENDENT LIVING COUNSELOR

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Preface

Independent Living is a concept expressive of people's desires to be in control of their own lives. To help in this regard, a number of independent living programs have developed around the country. One of the critical roles in these programs is that of the independent living counselor, and yet, very little has been written about this complex responsibility. Hence, this paper addresses the advocacy, counseling and case management skills needed by the independent living counselor. The paper closes with a case management tool which underscores the importance of needs assessment, goal-setting, and program monitoring.

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THE ROLE OF THE INDEPENDENT LIVING COUNSELOR

Introduction

The legal basis for the independent living counselor's role exists in Title VII of the Rehabilitation, Comprehensive Service, and Developmental Disabilities Amendments of 1978. Parts A and B of the 1978 Amendments present counseling as an essential service of independent living programs. Independent living counseling should be directed toward enabling the individual to meet personal needs in order to function more fully in home, community, and, if appropriate, employment.

Aspects of the independent living counselor's role can, therefore, be extracted from Parts A and B. Under Part A, the legislation requires state plans to provide assurances that:

1. an individualized written rehabilitation program will be developed for each handicapped person;
2. services will be rendered in accordance with the plan; and
3. periodic reviews of the individual's progress will be conducted.

In Part B, three general functions of the independent living counselor--intake counseling (needs assessment), referral, and advocacy--are described.

Based on the definitions in Parts A and B, the Seventh Institute on Rehabilitation Issues (1980) developed a job description for the "Coordinator of Independent Living Skills." Elements of this job description are:

1. Develop and implement an efficient intake system and follow-up mechanism.
2. Develop and implement a systematic approach for helping clients attain independent living skills.
3. Oversee the progress of specific clients by developing an individual plan (this will be the IWILP required by federal legislation), assess the attainment of stated goals, and be responsible for periodic reviews to revise the plan as necessary.
4. Make referrals both within the Independent Living Program and to community agencies.

5. Conduct extensive outreach programs to inform severely disabled individuals and/or their families of Independent Living Program resources.
6. Maintain close liaison with state rehabilitation staff to assure continuity of client service (p. 168).

To define the role of the independent living counselor, one can begin, therefore, with the responsibilities in the 1978 legislation and the interpretation of those duties in the job description for the "Coordinator of Independent Living Skills." But, it would also be helpful to view independent living counseling from the case advocate perspective discussed in the developmental disabilities literature (Baucom & Bensberg, 1976; Rude & Baucom, 1977).

In a recent article, Jessing and Dean (1976) stressed that the case advocate must have commitments and/or skills in the areas of philosophy of normalization, human and legal rights, individual program planning, and communication. Because these same four areas are important for the independent living counselor, this paper focuses on normalization as reflected in the independent living philosophy, human and legal rights, communication skills, and program planning skills.

Independent Living Philosophy

The independent living counselor must be aware of the contrast between the traditional rehabilitation model and the independent living model (DeJong, 1979). Too often, the rehabilitation paradigm has overemphasized the need for the individual to change in response to professional advice. Since the person's problems are viewed mainly as deficiencies in personal functioning which can be overcome through some "prescribed therapeutic regime" (DeJong, 1979, p. 442), the danger in the rehabilitation model is that the individual becomes an object to be "fixed" rather than an active participant in the helping process.

The independent living paradigm, on the other hand, views the environment as the primary source of the person's problems. By reducing certain physical and social barriers, the counselor can minimize many of the limitations experienced by individuals with severe disabilities. Viewing the counselor as an environmental change agent is certainly not new in the helping literature. For example, Lewis and Lewis (1977) noted several reasons for dealing with problems in the environment;

1. Negative aspects of the community environment may be detrimental to the growth and development of individuals.
2. Positive aspects of the community environment can support individual growth and development.
3. Counselors are helpless in their attempts to serve individuals when environmental factors do not change to keep pace with individual change (p. 357).

Trieschmann (1978; cited by DeJong, 1979) provided a long list of environmental factors which create problems for individuals with disabilities, e.g., the hospital milieu; stigma value of disability; family and interpersonal support; financial security; social milieu; urban versus rural residence; access to medical attention and equipment repair; access to education, recreation, and avocational pursuits; socioeconomic status; architectural barriers; availability of transportation; legislation; and cultural and ethnic influences. As an advocate for social and environmental change, the independent living counselor must conduct community information and education programs, work with legislators, and communicate the implications of legislation to employers and other affected groups.

Wright (1975) also dealt with the sensitivities required in independent living counseling. Stressing a coping framework, Wright (1975) reiterated the need to focus on what the person can do. Protracted consideration of limitations can begin to act as a pair of blinders causing independent living counselors to overlook the many areas in which the person can participate. Noting that positive outcomes can only be expected if both the person and environment are considered, Wright (1975) proposed the following strategies for helping individuals manage disability-related problems: "application of medical procedures, use of prostheses and aids, learning new skills, and environmental accommodation" (p. 219). Significant gains in environmental accommodation occur as the result of efforts to secure the human and legal rights of individuals with disabilities.

Human and Legal Rights

Protection and advocacy regarding a person's human and legal rights is a significant component of the case advocate role. The importance of protection and advocacy is also reflected in many of the definitions of independent living (Roberts, 1977). For example, these definitions stress participation to the fullest extent possible in work, home, family,

and social activities. The individual's right to appropriate and sufficient assistance from human service agencies is another facet of these definitions. Implicit in each of these definitions is a broader underlying principle, namely the individual's right to freedom of choice and personal control over one's life.

Freedom of choice and personal control over one's life can be fostered by the advocacy and protection services of the independent living counselor. These services should focus on specific rights of the person in both social and human service settings. In the social areas, rights of individuals with disabilities include the right to . . .

1. Make contracts
2. Hold professional, occupational, or vehicle driver's licenses
3. Make a will
4. Marry
5. Adopt or bear children
6. Hold and convey property
7. Access to publicly owned or financed buildings, publicly used but privately owned buildings, public streets, sidewalks, and transportation facilities and rolling stock
8. Equal educational opportunity in the least restrictive and denormalizing environment as possible
9. Equal employment opportunity
10. Just payment for labor
11. Equal access to medical services (Rigdon, 1977)
12. Vote and participate actively in political affairs

As Rigdon (1977) pointed out, "No person, including persons with physical or mental disabilities, either in the community or institutionalized in any way, should be deprived of the right to exercise constitutional and statutory rights belonging to all persons unless there has been a due process adjudication of such person's incompetence" (Rigdon, 1977, p. 61).

Because of their need for comprehensive services, individuals with severe disabilities may also need advocacy assistance with multiple social agencies. Cull and Levinson (1977) identified numerous rights of individuals who are involved in transactions with human service agencies, e.g., clients of human service agencies have the right to . . .

1. An explanation of the goals, functions, procedures, and operations of the agency

2. Referral and advocacy in instances where the agency contacted cannot help
3. An explanation of the appeal process
4. Full partnership in the selection of service providers and placements
5. Periodic review of the plan and modification, if needed, in the intermediate and long-range program objectives
6. Access to agency generated material related to the client
7. Prompt evaluation, eligibility decisions, and services
8. Advocacy services on their behalf
9. Free expression of their views regarding the quality of their program
10. High quality professional attention throughout the service process

The combined social and human services rights of the person provide an outline for the advocacy role of the independent living counselor. If they determine that individuals are being deprived of their rights, independent living counselors should initiate remedial action. Sometimes the counselor may be working to secure the rights of a single individual and, at other times, the rights of an entire class of individuals. For example, changes in legislation, agency policies, or community attitudes affect large groups of people. On the other hand, interventions with a specific service provider, creditor, parent, or guardian may benefit only a single individual.

Communication Skills

The assertive skills needed to be a good advocate are only part of the independent living counselor's role. The counselor must also have strong communication skills. Recent research (Blair & Fritz, 1980; Hodgson, 1981) indicates the effectiveness of interpersonal skills training with a variety of individuals. In addition to finding that rehabilitation counselors as a group functioned slightly above minimally facilitative levels on measures of interpersonal skills, Bozarth and Rubin (1975) reported that higher counselor levels of interpersonal skills were related to greater a) client vocational gains, b) monthly earnings at follow-up, c) positive psychological change, and d) job satisfaction. Carkhuff (1972; 1980) has also described additional studies documenting the positive effects of interpersonal skills on counseling outcomes.

Over time, the concept of interpersonal skills has evolved from a basic notion of core conditions--empathy, warmth, and genuineness--to a detailed description of concrete helping skills falling into the areas of attending, responding, personalizing, and initiating (Carkhuff, 1980). Attending skills emphasize those actions on the counselor's part which serve to establish the relationship, e.g., attending physically, communicating interest, observing body language, and listening for major problem areas.

To communicate an understanding of the person's problems, the counselor must use responding skills effectively. Responding skills enable the counselor to discriminate and communicate accurately the feelings and topics of significance in the other person's experience. Reflection of content and feelings enables the person to explore important areas of concern more fully.

Based on what they have learned from listening to individuals explore their problems, counselors then respond to the personal implications of the situation. Referred to as personalizing skills, these helping skills involve the helper in focusing on the individual's concerns in terms of meaning, feelings, and goals. During this phase, the person first comes to understand that the problem results from an inability to cope with difficult situations. Moreover, it becomes clear that constructive action will be needed if the problem is to be eliminated.

The bases for constructive action are established during the final stage of helping. In this phase, the counselor implements initiating skills to help the individual operationalize personal goals and develop and carry out steps to reach those goals. During this stage, the counselor's role is one of program development, monitoring, and revision. In independent living counseling, these programs often represent a combination of services from the independent living program and other agencies as well. Hence, the counselor must couple effective interpersonal skills with a strong commitment to helping individuals and their households receive maximum human services support (advocacy skills).

Case Management Skills

Another critical facet of the independent living counselor's role is case management. Part A of Title VII in the Rehabilitation Amendments of 1978 identified several phases of Case Management; 1) development of an individualized written rehabilitation program, 2) provision of services

according to the plan, and 3) review of the individual's progress toward program goals. Part B of the same legislation underscored the need for an efficient outreach, intake, and referral system. Hence, in describing the case management role of the independent living counselor, this paper focuses on the independent living counselor as a case finder, needs analyst, goal attainment specialist, and support system designer. The section closes with a suggested planning form for guiding the work of the independent living counselor.

Case Finder. Efficient utilization of program resources requires a steady flow of individuals seeking the services of the independent living center. Because of its recent development, the center may, however, not be well known in the community. Hence efforts will be needed to publicize the availability of center services and to establish regular referral channels.

A number of excellent referral sources exist for independent living centers. For example, centers should be notified regularly of those individuals who were considered ineligible for vocational rehabilitation services (Status 08) or who were not successful in completing their vocational rehabilitation programs (Status 28). In reviewing most of the referral sources to follow, the reader should keep in mind the dual need to publicize services and establish referral procedures. Other potential referral sources include:

1. Local physicians and hospitals
2. Physical therapy and/or occupational therapy organizations
3. Social services
4. Private and state employment agencies
5. Social Security
6. Self-referral
7. Friends and/or relatives
8. Churches
9. Community organizations
10. Home health teams
11. Public and private schools

Given a steady flow of consumers, the program must be prepared to identify their needs and develop appropriate independent living plans.

Needs Analyst. To understand concretely the potential problems of individuals seeking services, the independent living counselor must have a valid diagnostic scheme. One approach to needs assessment reflects the research of Sigelman,

Vengroff, and Spanhel (1979). They indicated that disability alters human functioning and performance in any or all of the following five areas: health, social-attitudinal, mobility, cognitive-intellectual and communication functions. A review of the literature on disability and its impact indicated that these five areas were "sufficiently comprehensive to classify all functional difficulties" (p. 105) even those resulting from mental retardation.

If limited in the health area, the person lacks the "physical well-being called good health" and "is characterized by functional impairments in one or more of the body's systems; . . ." Problems of self-acceptance and motivation for self-improvement are included in the social-attitudinal area. Mobility limitations include diminished capability to manipulate objects, move about home and work place, and participate in the affairs of the community. Impaired cognitive-intellectual functioning affects learning, memory, and generalization of learning. If limited in communication skills, the person "has difficulty sending and receiving messages, and exchanging information and ideas with other persons" (Sigelman, et al., 1979, p. 105). These five areas of human functioning were recently used as the basis for recommended approaches to evaluation of independent living programs (Roessler, 1981).

In reviewing the rehabilitation literature on disability related limitations, Sigelman, et al. (1979) found that most limitations would be included in the health area (32%). The percent of limitations attributed to each of the other four areas was as follows: social/attitudinal (26%), mobility (18%), cognitive/intellectual (12%), and communication (12%).

With the inclusion of the individual's financial situation, these five areas of human functioning could be used to structure an intake interview (Roessler, 1980). Consistent with the nominal group approach (Boland, 1978), the interview should begin with a general question as to the biggest problems the person is currently experiencing. After discussing these briefly, the individual could then rank them in order of importance so that the counselor would have some idea of the individual's priorities. A format for this approach is provided in Figure 1.

After a discussion of major problems suggested by the person seeking services, the independent living counselor should orient the interview more specifically to concerns in the health, mobility, cognitive/intellectual, communication,

Figure 1

Identifying Major Problems in Independent Living

"I would like us to begin by listing some things that seem to be your biggest problems. We'll just put them down as you think of them, then we'll come back, rank them in order of importance, and discuss them in detail."

Major Problems	Rank order in terms of importance (1-12)
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	_____
5. _____	_____
6. _____	_____
7. _____	_____
8. _____	_____
9. _____	_____
10. _____	_____
11. _____	_____
12. _____	_____

psychosocial, and financial areas. Probes for directing the individual toward relevant problems are included in the list to follow:

Major Problem Areas

Health Probes

Physical health
Strength/endurance
Stability of condition
Self-care

Eating	Grooming	Laundry
Cooking	Dressing	Sewing
Toileting	Housekeeping	Shopping

Attendant care

Mobility Probes

Transportation
- Automobile/van (private/public)
- Bus
- Family/friends
- Other

Accessibility of home
- Parking car
- Entry and exit
- Around house (bathroom, kitchen, bedroom, other living area)
- Manipulation of objects
- Use of appliances/devices in the home (kitchen, bathroom)

Accessibility of work place
- Parking
- Entry and exit
- Work area
- Restrooms
- Lunchroom/break area

Accessibility of recreational areas
- Parking
- Entry and exit
- Play areas
- Restrooms
- Eating areas

Other problems resulting from upper/lower body limitations (please list)

Cognitive/Intellectual Probes

- Reading
- Computing
- Self-expression (written/oral)
- Reasoning/Problem-solving (planning, scheduling and organizing daily activities)
- Memory (forgetfulness, difficulty in recall)

Communication Probes

- Capability to send and receive messages
  - Oral
  - Written
  - Aural
  - Visual
  - Potential mechanical aids needed

Social-attitudinal Probes

- Feelings about self (worries, nervousness)
- Relationships with others (conflicts, tension, arguments)
- Personal goals
- Participation in social activities
  - Work
  - Home
  - Community
  - Church

Financial Support Probes

- Income (adequacy)
- Money management (budgeting, savings)
- Health and medical benefits
- Food stamps
- Housing subsidies (rent, house payments)
- Child care

After identifying problems through the open-ended question and the probes for each of the six areas, the counselor should help the individual develop objectives for the independent living plan. Objective statements should indicate the performance desired, the level of performance required to resolve the problem, and a deadline for achieving the objective (See Roessler's 1981 report entitled "Strategies for evaluating independent living programs" for lists of independent living objectives and measurement approaches).

It is also possible to chart changes in an individual's independent living status more globally. For example, an independent living program could contribute to desirable changes in handicap status (modified from Wood, 1980), living status, vocational rehabilitation status, involvement with community agencies, and employment status. Figure 2 presents scales for evaluating changes in these areas from initiation (I) to completion (F) of independent living services. By entering a checkmark in the I or F column, the counselor can indicate the individual's beginning or final level in a particular independent living status. Although it may not always hold for the number of community agencies involved, the higher the number of the level the more desirable it is. As a result of independent living services, the individual would be expected to move from lower to higher levels. Improvement in these independent living statuses represents valuable feedback which the counselor can share with the individual.

Service Arranger, Provider, and Coordinator. Recent surveys identify the services needed by individuals with severe disabilities. For example, Clowers and Belcher (1978) noted that some of the most frequently requested services by severely disabled people include transportation for work, attendant care, home modification, and speech therapy. As a result of an evaluation of ten independent living centers in California, Stoddard (1980) reported that the following were the most frequent service-related requests: counseling, other places to get help, attendant care, get a ride, talk to people with similar disabilities, find a new place to live, and meet people. A further analysis of the service data in Stoddard's (1980) report revealed eight broad categories of needed services. These areas and related concerns are depicted in Figure 3.

Another way to approach the counselor's service arranging, providing, and coordinating function is to view services in terms of needs in the various areas of human functioning. For example, using two recent listings of services in independent living (Belcher & Clowers, 1979; Stoddard, 1980), it is possible to assign service responses to problems in the health, social-attitudinal, mobility, cognitive-intellectual, communication, and financial areas (See Figure 4). Because they pertain to all of the areas of human functioning in Figure 4,

Figure 2

Global Independent Living Outcomes

(I = Initial Status, F = Final Status)

Long-Term Status Changes

Living Status

1. ____I ____F Nursing Home
2. ____I ____F Parent's Home
3. ____I ____F Attendant, own home or apartment
4. ____I ____F Alone or family, own home or apartment

Involvement with Community Agencies (Receiving ongoing services)

1. ____I ____F 0 agencies
2. ____I ____F 1-2
3. ____I ____F 3-5
4. ____I ____F 5+

Vocational Rehabilitation Status

1. ____I ____F Closed nonfeasible
2. ____I ____F No contact
3. ____I ____F Referred, not accepted
4. ____I ____F Accepted for services

Employment Status

1. ____I ____F Unemployed
2. ____I ____F Workshop employment
3. ____I ____F In vocational training for competitive employment
4. ____I ____F Competitive employment, part-time
5. ____I ____F Competitive employment, full-time

Handicap Status*

1. Orientation Handicap (Or) - problems in seeing, listening, touching, speaking, understanding, remembering, concentrating, perceiving, behaving and/or consciousness).

   6. ____I ____F Fully oriented
   5. ____I ____F Fully compensated impediment to Or
   4. ____I ____F Partially compensated impediment to Or
   3. ____I ____F Moderate impediment to Or
   2. ____I ____F Severe impediment
   1. ____I ____F Orientation deprivation

2. Physical Independence Handicap (P) - extent of dependence on aids, persons, or necessary modifications in the environment.

   7. ____I ____F Fully independent
   6. ____I ____F Aided independence
   5. ____I ____F Adapted independence
   4. ____I ____F Situational dependence
   3. ____I ____F Short-interval dependence
   2. ____I ____F Long-interval dependence
   1. ____I ____F Intensive care dependence

Figure 2 (Continued)

3. Mobility Handicap (M) - degree of difficulty moving around in one's surroundings.

7.	____I	____F	Fully mobile
6.	____I	____F	Variable restriction of M
5.	____I	____F	Neighborhood restriction
4.	____I	____F	Dwelling restriction
3.	____I	____F	Room restriction
2.	____I	____F	Chair restriction
1.	____I	____F	Total restriction of M

4. Occupational Handicap (O) - degree to which person occupies his/her time in the manner customary to his/her sex, age, and culture; e.g., employment, school, and recreation.

6.	____I	____F	Customarily occupied
5.	____I	____F	Intermittently unoccupied
4.	____I	____F	Curtailed O
3.	____I	____F	Confined O
2.	____I	____F	No O
1.	____I	____F	Unoccupiable

5. Social Integration Handicap (S) - degree to which person participates in and maintains customary social relationships.

6.	____I	____F	Socially integrated
5.	____I	____F	Inhibited participation
4.	____I	____F	Impoverished relationships
3.	____I	____F	Disturbed relationships
2.	____I	____F	Alienated
1.	____I	____F	Socially isolated

6. Economic Self-sufficiency Handicap (E) - degree to which person can sustain customary socioeconomic activity and independence.

5.	____I	____F	Fully self-sufficient
4.	____I	____F	Adjusted self-sufficiency
3.	____I	____F	Precariously self-sufficient
2.	____I	____F	Economically deprived
1.	____I	____F	Impoverished

*See Wood (1980) for additional handicap levels and a full description of the handicap status system.

Figure 3

Services Needed by Individuals with Severe Disabilities

Advice and Advocacy

- Advice from counselor
- Legal help
- Help identifying resources of other agencies
- Help dealing with an agency

Equipment/Aids

- Get or use special devices or equipment
- Equipment repaired

Housing

- New place to live
- Improve housing situation
- Help with landlord

Employment Oriented

- Help finding a job or vocational training
- Help dealing with DVR
- Help with an employer

Attendant Care

- Screening
- Training
- Current referral lists

Social Support

- Talk to people with similar problems
- Meet people

Transportation

- Access to mass transportation
- Specially equipped vehicles

Readers/Interpreters

Figure 4

Independent Living Services Indexed to the Six Areas of Human Functioning

Health

Surgery
Hospitalization
Physical Therapy[a]
Occupational Therapy[a]
Dental
General Medical
Visiting Nurse
Homemaker Service[a]
Prosthetic Devices[a]
Attendant Care[a] [b]
Sex Therapy
Attendant Training

Social-attitudinal

Vocational Counseling[a]
Psychological Therapy
Social Services[a]
Peer Counseling
Family Counseling
Family Training
Therapeutic Recreation

Mobility

Transportation[a]
Home Remodeling[a] [b]
Mobility Instruction
Equipment/Vehicle (access repair, modification)

Cognitive-Intellectual

Vocational Training[a]
Educational Training Costs[a]
Vocational Placement[a]
Receipt of Tools
Job Seeking Training

Communication

Speech and Hearing[a]
Interpreters/TTY
Reader/Braille Services

Financial

Financial/Benefits Counseling[a] [b]

---

[a]Requested by more than 20% of the individuals in Belcher and Clowers' survey (1979).

[b]Provided by at least 50% of the independent living centers surveyed by Stoddard (1980).

general advocacy services aimed at significant environmental changes (physical, social, financial, and human service environments) are not noted in Figure 4. Stoddard's review (1980) of ten independent living centers indicated that all ten centers (100%) provide general advocacy services. Fifty percent (50%) of the centers offer legal consultation, and forty percent (40%) provide personal advocacy with other community agencies serving the center's clientele.

Having helped the individual select appropriate independent living services, the counselor must then determine how these services can be provided, e.g., by the counselor, the independent living center, and/or by other community, state, and federal agencies. Selecting the services for the plan is, therefore, the basis for making provisions to refer the person and/or household members to the appropriate agencies. Belcher and Clowers (1979) and Counts and Opdahl (1979) reported that the following agencies or programs have benefits or services of value: Social Security (Supplementary Security Income, Social Security Disability Insurance), Medicaid, Medicare, public assistance, food stamps, Title XX, housing authority, state vocational rehabilitation agency, crippled children's programs, developmental disability programs, state employment agency, and vocational training programs. An even more extensive list of agencies indexed in terms of potential services in housing, transportation, attendant care, health services, vocational services, recreation, and counseling was presented in "Implementation of independent living programs in rehabilitation" (Seventh Institute on Rehabilitation Issues, 1980).

Overall, several conclusions can be drawn regarding independent living services. First, since they must deal with several agencies at one time, individuals need the coordination and advocacy services which the independent living counselor can provide. Second, given the vast number of programs with valuable benefits, individuals need someone who can serve as an information source. The independent living counselor must, therefore, be a service information resource. Finally, perseverance, imagination, and creativity are desirable characteristics of independent living counselors as they dispense their responsibilities of service arranger, provider, and coordinator. In this regard, Counts and Opdahl (1979) stated:

> Counselors choosing the path of working on independent living caseloads must develop additional expertise in managing similar benefits, exploring the community for novel service delivery mechanisms,

> strengthening ties with rehabilitation engineers, becoming more familiar with needs of specific disability types, securing strong consumer support in the community, and assisting community programs to expand their services . . . (p. 196).

Goal Attainment Specialist. As a foundation for their responsibilities in needs analysis, goal-setting, and service arrangement, independent living counselors must have an understanding of the factors which encourage or impede goal-oriented behavior. For example, the degree to which a person will expend effort to achieve a goal is related to several crucial factors--the personal cost in terms of time, money, pain, or effort to achieve the goal; the subjective probability of a successful outcome; and the meaning or value (utility) the person attaches to the "performance of the task and attainment of the objective" (McDaniel, 1976, p. 128).

Given these elements of a motivational model--cost, subjective probability, and utility--the independent living counselor must be certain that the individual sees the connection between personal needs in the health, social-attitudinal, mobility, cognitive-intellectual, communication, and financial areas and the expected outcomes of independent living services. For example, the utility question is dealt with if the needs expressed by the person are both genuine and pressing. Issues of cost and probability can be addressed during the counseling sessions. Is attainment of the objective too costly from the person's point of view or is the probability of success seen as too low to make action worth initiating? For example, individuals may decide that continuation of certain physical therapy exercises is simply too painful. Similarly, they may conclude that there is no point in following an exercise regimen because they will never regain full use of their hands.

To encourage goal-seeking, therefore, the counselor must help the person examine and deal with relevant cost, utility, and probability factors. Strategies for reducing the negative impact of each of those factors should be built into the plan, e.g., environmental modifications, transportation, personal counseling, medical care, etc.

The independent living counselor should also be familiar with basic principles in the goal-setting literature (Locke, Saari, Shaw, & Latham, 1981; McDaniel, 1976; Roessler, 1980; Sands & Kraus, 1975; & Zane, 1961). For example, goal attainment is enhanced if the counselor:

1. Starts with the most immediate, pressing needs expressed by the person.
2. Determines the person's personal expectations regarding goal attainment. If those expectations are negative, the counselor should ascertain the reasons for the negative expectations. In some cases, individuals may believe that they do not know how to achieve the goal; in other cases, they may feel they understand the steps but have a low probability of succeeding. The counselor must understand how strategies such as guided practice, modeling, feedback, encouragement, and reinforcement can be used to deal with negative expectations.
3. Breaks the goals into smaller compatible sub-goals for which effort on the person's part can be reinforced.
4. Demonsrates the relationship of the smaller steps to overarching goals of a more independent and fulfilling life.
5. Points out instances of success to reduce the person's level of stress and build expectations of goal success.
6. Identifies feasible responses to barriers in the physical, social, financial, and/or human service environments.

Therefore, to discuss progress in independent living is to enter into a careful analysis of why the person does or does not achieve a goal. Many problems can be more successfully attacked if one looks at the following issues: a) the value of the goal to the individual (does a state of need exist?), b) the expectation of success associated with the goal (does the person believe that goal attainment is possible?), c) the feelings associated with attempts to attain the goal (is progress toward the goal perceived and self-reinforcing?), d) the support from significant others to attain the goal (are family and friends providing social reinforcement?), and, finally, e) the barriers to goal attainment in the person or in the world (how is the person or the environment impeding progress toward the objective?). Ample research data (McClelland, 1961; McClelland, Atkinson, Clark, & Lowell, 1953) exist to support the relevance of each of these areas to a better understanding of gain or loss in independent living.

To have accurate information on factors affecting goal attainment, the counselor must monitor the individual's progress carefully. Progress can be determined by estimating

the extent to which the gap between the person's current status and the expected outcome closes over time. Of course, many factors can affect the person's progress. For example, the counselor needs to learn whether the individual . . .

1. is actually following the steps or the plan
2. is on schedule in achieving certain intermediate gains related to the overall goal
3. still views the program as something he/she wants and needs.

Sands and Kraus (1975) also recommended that the counselor carefully analyze the factors which are impeding the person's progress. As the Achievement Motivation model stresses (McClelland, 1961), these barriers may be in the world or the person. Once barriers have been identified, the independent living counselor and the person need to list them in order of importance and devise a strategy to deal with the most important one first. This strategy should be implemented and followed until the barrier is no longer an issue. Often in removing one significant barrier the individual may find that a number of other problems have been resolved as well. Hence, the person and the counselor should reanalyze the salience of remaining barriers and work to eliminate the next most pressing concern.

Support System Designer. Before terminating formal contact with the person, the independent living counselor should determine which needs have been met and which require some long-term support. For example, the individual may have developed certain self-care skills, received certain equipment and/or housing modifications, and developed additional recreational outlets. At the same time, continuing need may exist for financial maintenance, transportation, attendant care, equipment repair, and communication support from interpreters or readers. Therefore, the independent living counselor should place high priority on establishing a functional, long-term support program designed so that the person and/or spouse and family can implement it with little outside assistance. Creation of such a program would signify the end of active involvement by the counselor except for periodic follow-up, e.g. annually, with the person. An example of an independent living plan which calls for establishment of a long-term support plan is discussed in the next section.

A Case Management Form For Independent Living Counseling. Independent living counseling tasks are reflected in Figure 5,

Figure 5

Independent Living Rehabilitation Plan

Primary Person Household Members

Names: 1. _____ 2. _____ 3. _____ 4. _____ 5. _____ 6. _____

Household Member #	Needs[a]	Services and Sources	Expected Outcome and Date	Barriers/Resolutions	Actual Outcome and Date

[a]Needs-Health, Social-Attitudinal, Mobility, Cognitive-Intellectual, Communication, and Financial

Comments on Program Progress (note date of contact)	Needed Long-term Services				Dates of Annual Follow-ups
		In Place	To be Secured		In Place	To be Secured	
	Financial	—	—	Equipment Repair	—	—	
	Attendant Care	—	—	Social Support	—	—	
	Transportation	—	—	Housing	—	—	
	Medical (specify)			Other (specify)			
	1	—	—	1	—	—	
	2	—	—	2	—	—	

Global Outcomes (I = Initial Status, F = Final Status; ✓ to indicate level)

Long-term Changes Living Status	Vocational Rehabilitation Status	Involvement with community agencies (receiving ongoing services)	Employment Status
1. ___I ___F Nursing home	1. ___I ___F Closed nonfeasible	1. ___I ___F 0 agencies	1. ___I ___F Unemployed
2. ___I ___F Parent's home	2. ___I ___F No Contact	2. ___I ___F 1-2	2. ___I ___F Workshop employment
3. ___I ___F Attendant, own home or apartment	3. ___I ___F Referred, not accepted	3. ___I ___F 3-5	3. ___I ___F In vocational training for competitive employment
4. ___I ___F Alone or family, own home or apartment	4. ___I ___F Accepted for services	4. ___I ___F 5+	4. ___I ___F Competitive employment, part-time
			5. ___I ___F Competitive employment, full-time

Handicap Status Changes (Enter number of functioning level)

Orientation ___I ___F	Mobility ___I ___F	Social Integration ___I ___F
Physical Independence ___I ___F	Occupational ___I ___F	Economic Self-sufficiency ___I ___F

Figure 5 (Continued)

Handicap Status Changes

1. Orientation Handicap (Or) - problems in seeing, listening, touching, speaking, understanding, remembering, concentrating, perceiving, behaving, and/or consciousness.

   6. ___I ___F Fully oriented
   5. ___I ___F Fully compensated impediment to Or
   4. ___I ___F Partially compensated impediment to Or
   3. ___I ___F Moderate impediment to Or
   2. ___I ___F Severe impediment
   1. ___I ___F Orientation deprivation

2. Physical Independence Handicap (P) - extent of dependence on aids, persons, or necessary modifications in the environment.

   7. ___I ___F Fully independent
   6. ___I ___F Aided independence
   5. ___I ___F Adapted independence
   4. ___I ___F Situational dependence
   3. ___I ___F Short-interval dependence
   2. ___I ___F Long-interval dependence
   1. ___I ___F Intensive care dependence

3. Mobility Handicap (M) - degree of difficulty moving around in one's surroundings.

   7. ___I ___F Fully mobile
   6. ___I ___F Variable restriction of M
   5. ___I ___F Neighborhood restriction
   4. ___I ___F Dwelling restriction
   3. ___I ___F Room restriction
   2. ___I ___F Chair restriction
   1. ___I ___F Total restriction of M

4. Occupational Handicap (O) - degree to which person occupies his/her time in the manner customary to his/her sex, age, and culture; e.g., employment, school, and recreation.

   6. ___I ___F Customarily occupied
   5. ___I ___F Intermittently unoccupied
   4. ___I ___F Curtailed O
   3. ___I ___F Confined O
   2. ___I ___F No O
   1. ___I ___F Unoccupiable

5. Social Integration Handicap (S) - degree to which person participates in and maintains customary social relationships.

   6. ___I ___F Socially integrated
   5. ___I ___F Inhibited participation
   4. ___I ___F Impoverished relationships
   3. ___I ___F Disturbed relationships
   2. ___I ___F Alienated
   1. ___I ___F Socially isolated

6. Economic Self-sufficiency Handicap (E) - degree to which person can sustain customary socioeconomic activity and independence.

   5. ___I ___F Fully self-sufficient
   4. ___I ___F Adjusted self-sufficiency
   3. ___I ___F Precariously self-sufficient
   2. ___I ___F Economically deprived
   1. ___I ___F Impoverished

the Independent Living Rehabilitation Plan. Figure 5 represents a concrete reminder or, better yet, an actual record of the steps and results involved in independent living counseling. For example, the first step in case management is the identification of the primary person (the individual seeking services) and the other members of the household who need services. Then personal and family member needs in the areas of human functioning mentioned previously--health, social-attitudinal, mobility, cognitive-intellectual, communication, and financial--must be identified and related to services needed and appropriate referrals (if necessary). Expected outcomes of the services are delineated followed by specification of any barriers and requisite strategies related to attainment of service objectives and need fulfillment.

Monitoring of goal attainment is achieved through periodic contact with the person. The purpose of these follow-up contacts is to provide feedback, reinforce progress, and secure outcome data. Outcome data pertain to expected results of the program which eventually provide a foundation for long-term changes in independent living status, e.g., desirable changes in living, vocational rehabilitation, employment, community agency, and handicap statuses.

Before ending formal contact with the person, the independent living counselor must indicate what services are needed on a long-term basis and whether these services are in place or yet to be secured. The case should not be placed in an annual follow-up status until a satisfactory support system exists.

Conclusions and Recommendations

Maintaining the momentum of independent living is critical at this point in history. Even though it offers beneficial services for individuals with severe disabilities, Title VII of the 1978 Rehabilitation Act Amendments has not been adequately funded. Without additional financial support for the independent living movement, many of the concerns in this report become somewhat academic. Nevertheless, if it is to respond appropriately, the field of independent living must continually analyze its responsibilities and effectiveness.

Playing a crucial role in the overall service program, the independent living counselor must be committed to the independent living philosophy and to advocacy for individual legal and human service rights. In addition, the counselor must be proficient in interpersonal and case management skills.

As case managers, counselors are involved in case finding, needs analysis, goal-attainment, and support system designing. Evidence of the application of these case management skills should be clearly documented in the case file of individuals receiving independent living services.

Based on the material in this report, the following conclusions and recommendations were drafted:

1. Conclusion

Persons with severe disabilities have family situations which either enhance or impair their independent living capabilities.

Recommendation

Independent living counselors should consider not only the needs of the individual seeking services but also the needs of other household members. Referrals of family members to appropriate agencies should, therefore, also be part of the independent living plan.

2. Conclusion

The case finding, needs analysis, goal attainment, and support system designing functions of independent living counselors comprise their case management responsibilities.

Recommendation

Independent living counselors must monitor their own activity to determine whether they are performing effectively in all facets of their role. An independent living plan requiring them to record results of case work is, therefore, a useful device. This plan should call attention to short and long-term individual needs, the agencies and services required to meet those needs, expected outcomes of the plan, barriers to service success and need fulfillment, results of goal attainment monitoring, and a long-term service program which the person can manage without outside assistance.

3. Conclusion

Independent living counseling is based on two essential principles; the person seeking services is

viewed as an independent, self-directed individual capable of managing his/her life and the social and physical environment is the major handicapping force in the life of individuals with disabilities.

Recommendation

Independent living counselors must take their advocacy responsibilities very seriously. They must initiate changes in the health care system which enhance the status of the person seeking services. They must initiate changes in the physical, social, financial, and human service environments which reduce barriers to independent living. Inaccessible housing, recreational programs, and work places; financial disincentives to employment; shrinking resources for attendant care and equipment; and prejudicial social attitudes represent a few of the environmental barriers which have handicapping effects.

4. Conclusion

Independent living counselors also have a strong therapeutic role to play. The level of the counselor's interpersonal skills influences the success of the independent living plan.

Recommendation

Independent living counselors should receive training in interpersonal skills. Communication skills on the counselor's part increase the probability that people seeking independent living services will express and meet their independent living needs.

5. Conclusion

Independent living counselors need a comprehensive scheme for diagnosing independent living needs. These schemes must focus on the effect of severe disability on human functioning in physical and social environments.

Recommendation

Independent living counselors should develop a diagnostic approach that results in identification of limitations in the areas of health, social-attitudinal, mobility, cognitive-intellectual, communication, and financial functioning. Gains in these areas can result

from environmental changes, development of the individual's skills, and additional health or financial benefits.

6. Conclusion

Needs in the health, social-attitudinal, mobility, cognitive-intellectual, communication, and financial areas can be translated into goals which the person wishes to achieve.

Recommendation

Independent living counselors should help individuals see the connection between needs and goals. For example, the need to have additional friends and greater participation in society may involve the development of new social skills, identification of additional recreational outlets in the community, and creation of a transportation program which makes further social contacts possible. Stating goals sets the stage for developing observable outcomes for the independent living plan.

7. Conclusion

Independent living needs are the basis for creation of a service program. Some services will be provided directly by the independent living counselor. Others will be secured from community, state, and federal human service programs.

Recommendation

Survey results underscore the need for counselors to provide responses to needs of severely disabled individuals in the following areas: advice and advocacy, attendant care, equipment and aids, social support, housing, transportation, employment, and readers and interpreters. Service responses can be categorized in terms of their potential to increase human functioning in specific areas. For example, mobility functioning could be enhanced by additional transportation, home remodeling, mobility instruction, and equipment or vehicle repair or modification. Specific agencies providing significant independent living benefits are Social Security, Medicare/Medicaid, Social Services, Title XX, Department of Housing and Urban Development,

state rehabilitation programs, developmental disability programs, and state employment agencies. Individuals need assistance in securing and managing services from these programs during the early phases of their independent living program.

8. Conclusion

As in any other area of human performance, independent living is affected by certain basic motivational factors. Independent living counselors can utilize an understanding of task performance in helping individuals implement their independent living plans.

Recommendation

Rather than attribute failure to attain goals to "lack of motivation" on the person's part, counselors should examine the influence of cost, subjective probability, and utility factors. To overcome problems in any one of those areas, the counselor may need to help the person understand the relationship between personal and household needs and independent living services (utility). The individual may also need support from the counselor or services in other areas to decrease the influence of cost and subjective probability factors. In the case of program failure, counselors may also need to determine whether the plan violates any of the basic principles of goal-setting; e.g., start with the most pressing needs, break complex goals into smaller, compatible subgoals, etc.

9. Conclusion

Goal attainment is enhanced by periodic feedback and reinforcement. Individuals need knowledge of their results and recognition of their progress.

Recommendation

Monitoring goal attainment should be a regular activity of the independent living counselor. By relating the individual's status over time on certain goals to needs at intake, the counselor can a) determine whether progress has occurred, b) acknowledge and reinforce the progress, and/or c) develop new steps in the plan to increase the probability that the individual will succeed. Removal of barriers to progress whether they be environmental or personal is an important outcome of monitoring activities.

10. Conclusion

Many independent living needs require long-term services, e.g., attendant care, financial maintenance, transportation, and equipment repair. Cases should not be closed and scheduled for annual reviews unless steps have been taken to meet those long-term needs.

Recommendation

Before closing a case, independent living counselors should take two steps. First, they should determine that short-term needs such as housing modification; independent living, self-care or social skills training; and equipment have been met. Then they must teach the person and spouse and/or family how to maintain agency services and benefits to meet ongoing needs. When a long-term program is in place, the counselor should then schedule annual contacts with the person to determine whether it is operating satisfactorily.

References

Baucom, L. & Bensberg, G. Advocacy systems for persons with developmental disabilities. Research and Training Center in Mental Retardation, Texas Tech University, Lubbock, TX, 1976.

Belcher, S., & Clowers, M. Service delivery for the severely disabled individual: Follow-up. Journal of Applied Rehabilitation Counseling, 1979, 9(4), 178-188.

Blair, M. & Fritz, B. Interpersonal skills training for premedical students, Journal of Counseling Psychology, 1980, 27(4), 380-384.

Boland, Jeanne. The nominal group process in vocational rehabilitation. Rehabilitation Counseling Bulletin, 1978, 21(4), 335-338.

Bozarth, J. & Rubin, S. Empirical observations of rehabilitation performance and outcome: some implications. Rehabilitation Counseling Bulletin, 1975, 19(1), 294-299.

Carkhuff, R. The Art of Helping IV. Human Resource Development Press (4th Ed.), 1980, Amherst, Mass.

Carkhuff, R. The development of systematic human resource development models. The Counseling Psychologist, 1972, 3(3), 4-11.

Clowers, M., & Belcher, S. Service delivery for the severely disabled individual: Needs and services. Journal of Applied Rehabilitation Counseling, 1978, 9(3), 108-115. (a)

Clowers, M., & Belcher, S. A service delivery model for the severely disabled individual: Accountability data-collection system. Rehabilitation Counseling Bulletin, 1978, 22(1), 53-59. (b)

Counts, R., & Opdahl, C. Independent living rehabilitation for blind-multihandicapped persons. Journal of Rehabilitation Counseling, 1979, 10(2), 193-199.

Cull, J. & Levinson, K. The rights of consumers of rehabilitation services. Journal of Rehabilitation, 1977, 43(3), 29-32.

DeJong, G. Independent living: From social movement to analytic paradigm. Archives of Physical Medicine, 1979, 60, 435-446.

Hodgson, J. Cognitive versus behavioral-interpersonal approaches to the group treatment of depressed college students. Journal of Counseling Psychology, 1981, 28(3), 243-249.

Jessing, B. & Dean, S. Case advocacy: ideology and operation. In Baucom, L. & Bensberg, B. Advocacy systems for persons with developmental disabilities, 1976, pp. 141-160.

Lewis, M., & Lewis, J. The counselor's impact on community environments. Personnel and Guidance Journal, 1977, 55(6), 356-358.

Locke, E., Saari, L., Shaw, K., & Latham, G. Goal-setting and task performance: 1969-1980. Psychological Bulletin, 1981, 90(1), 125-152.

McClelland, D. C. The achieving society. Princeton: Van Nostand, 1961.

McClelland, D. C., Atkinson, J. W., Clark, R. A., & Lowell, E. L. The achievement motive. New York: Appleton-Century, 19 3.

McDaniel, J. Physical disability and human behavior. 2nd Ed. New York: Pergamon Press, 1976.

Rigdon, L. Civil rights of the handicapped. White House Conference on Handicapped Individuals, 1977, Washington, D. C., 59-64.

Roberts, E. Foreword. In Stoddard-Pflueger, S., (Ed.). Emerging issues in rehabilitation, Institute for Research Utilization, Washington, D. C., 1977.

Roessler, R. An independent living need survey. Arkansas Rehabilitation Research and Training Center, University of Arkansas, Fayetteville, 1980 (unpublished document).

Roessler, R. Factors affecting client achievement of rehabilitation goals. Journal of Applied Rehabilitation Counseling, 1980, 11(4), 169-173.

Roessler, R. Strategies for evaluating independent living programs. Arkansas Rehabilitation Research and Training Center, Fayetteville, AR, 1981.

Roessler, R., Mack, G., & Statler, J. Experimental case management: A pilot manual for training case managers in service coordination projects. Training Manual, Arkansas Rehabilitation Research and Training Center, Fayetteville, AR, 1975.

Roessler, R., & Rubin, S. Goal-setting: Guidelines for diagnosis and program development. Arkansas Rehabilitation Research and Training Center, Fayetteville, AR, 1980.

Rude, C. & Baucom, L. (eds.). Implementing protection and advocacy systems. Research and Training Center in Mental Retardation, Texas Tech University, Lubbock, TX, 1977.

Sands, H., & Kraus, C. Personal adjustment counseling for persons with epilepsy. In G. Wright (Ed.), Epilepsy rehabilitation. Boston: Little, Brown and Company, 1975, pp. 104-121.

Seventh Institute on Rehabilitation Issues. Implementation of independent living programs in rehabilitation. Arkansas Rehabilitation Research and Training Center, 1980.

Sigelman, C., Vengroff, L., & Spanhel, C. Disabilities and the concept of life function. Rehabilitation Counseling Bulletin, 1979, 23(2), 103-113.

Stoddard, S. Evaluation report on the state's independent living centers (Funded by AB204). Berkeley Planning Associates, Berkeley, CA, 1980.

Trieschmann, R. B. The psychological, social, and vocational adjustment of SCI: A strategy for future research--final report. Los Angeles Easter Seal Society, 1978.

Wood, P. Impairment, disability, handicap: Toward the development of a functional information system. Great Britain: University of Manchester, 1980.

Wright, B. Social-psychological leads to enhance rehabilitation effectiveness. Rehabilitation Counseling Bulletin, 1975, 18(4), 214-223.

Zane, T. The geriatric amputee. Washington, D. C.: National Academy of Scientific Publishers, 1961.